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Research in Developmental Disabilities



Prevalence of chronic diseases in adolescents with intellectual disability

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ABSTRACT

Valid community-based data on the prevalence of chronic diseases in adolescents (12–18 years) with intellectual disability (ID-adolescents) are scarce. The aim of this study was to assess the prevalence rates and the nature of chronic diseases in a population of ID-adolescents and to compare them with the rates among adolescents in the general population. Therefore, we obtained data on 1083 ID-adolescents attending secondary schools, day care centers or living in residential centers fully covering one region of the Netherlands. Parents of the adolescents completed a questionnaire about the occurrence of chronic diseases in their child during the previous 12 months and about background characteristics. The questionnaire was derived from the Dutch National Permanent Survey on Living Conditions questionnaire periodically administered in a representative population sample ($n \approx 10,000$). Prevalence rates of chronic diseases in ID-adolescents were compared with those in adolescents in the Dutch general population. Among ID-adolescents, high prevalence rates of a wide range of chronic diseases were found. The five most prevalent were: ADHD (21.1%), PDD-NOS (14.0%), dyslexia (13.9%), migraine or chronic headache (12.7%), and autistic disorder (10.9%). These prevalence rates were all higher ($p < 0.05$) than among adolescents in the general population. Of all ID-adolescents, 62.9% was reported to have at least one chronic disease. The burden of chronic diseases among ID-adolescents is very high, showing a high need for adequate care. These high prevalence rates should alert policymakers and clinicians regarding the widespread of chronic diseases among ID-adolescents.

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1. Introduction

Valid community-based data on the prevalence rates of the full range of chronic diseases in adolescents (12–18 years) with intellectual disability (ID-adolescents) are scarce (Sawyer, Drew, Yeo, & Britto, 2007; Van Schrojenstein Lantman-de Valk & Walsh, 2008). A number of studies have reported on the prevalence of specific chronic diseases in young people with ID (Airaksinen et al., 2000; Bradley & Bolton, 2006; Bradley & Isaacs, 2006; Bryson, Bradley, Thompson, & Wainwright, 2008; Cans et al., 1999; Christianson et al., 2002; de Bildt, Sytema, Kraijer, & Minderaa, 2005; Dekker & Koot, 2003; Emerson & Hatton, 2007; Emerson, 2003; Fernell, 1998; Gothelf et al., 2008; Hou, Wang, & Chuang, 1998; Jelliffe-Pawlowski, Shaw, Nelson, & Harris, 2003; Koskentausta, Iivanainen, & Almqvist, 2002; Lewis et al., 2000; Magnusson & Saemundsen, 2001; Merrick & Morag, 2000; Molteno, Molteno, Finchilescu, & Dawes, 2001; Morgan, Baxter, & Kerr, 2003; Nielsen, Skov, & Jensen,

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2007a; Nielsen, Skov, & Jensen, 2007b; Nordin & Gillberg, 1996; Petterson, Bourke, Leonard, Jacoby, & Bower, 2007; Steffenburg, Gillberg, & Steffenburg, 1996; Stromme & Diseth, 2000; Stromme & Hagberg, 2000; Van Schrojenstein Lantman-de Valk, van den Akker, Maaskant, & Haveman, 1997; Voigt, Barbaresi, Colligan, Weaver, & Katusic, 2006; Yeargin-Allsopp, Murphy, Cordero, Decoufle, & Hollowell, 1997; Zhang & Ji, 2005). However, only few studies have reported such prevalence rates of a wide range of chronic diseases associated with ID (Fernell, 1998; Stromme & Diseth, 2000; Stromme & Hagberg, 2000; Van Schrojenstein Lantman-de Valk et al., 1997). Moreover, only some studies compared their results with the prevalence rates of chronic diseases in the general population (Emerson & Hatton, 2007; Emerson, 2003; Magnusson & Saemundsen, 2001; Petterson et al., 2007; Voigt et al., 2006), and none of these studies reported prevalence rates of chronic diseases among ID-adolescents.

Adolescence is a specific stage of life between child- and adulthood with specific health needs. It is a time of life marked by physical, emotional, behavioural and social changes, but also by relatively high risks for the onset of (chronic) health problems (Patton & Viner, 2007; Sawyer et al., 2007; Turk, Graham, & Verhulst, 2007). Literature about young people with ID suggests that adolescents have a greater risk on chronic diseases compared to adolescents without ID (Cooper, Melville, & Morrison, 2004; Emerson & Hatton, 2007; Emerson, 2003; Jansen, Krol, Groothoff, & Post, 2004; Kolaitis, 2008; Magnusson & Saemundsen, 2001; Petterson et al., 2007; Van Schrojenstein Lantman-de Valk & Walsh, 2008; Voigt et al., 2006), but inclusive data on this are lacking.

Age-specific community-based data are thus needed to support policymakers and professionals in the adequate provision and planning of care to ID-adolescents. Policymakers need these data for the planning and financing of adequate care arrangements (e.g. health, education, work) to enhance the well being and societal participation of ID-adolescents and their families. Professionals need these data to know who are at risk for chronic diseases and to prevent chronic diseases, to support the early detection and adequate treatment of chronic diseases and their consequences among ID-adolescents and their families (American Association on Mental Retardation, 2002; Goddard, Davidson, Daly, & Mackey, 2008; McDermott, Durkin, Schupf, & Stein, 2007; Newacheck, Rising, & Kim, 2006).

The aim of this study is: (1) to assess the prevalence and the nature of chronic diseases in a population of ID-adolescents; (2) to compare the prevalence rates of chronic diseases in ID-adolescents with that among adolescents in the general population.

2. Methods

2.1. Participants

2.1.1. Adolescents with ID

We collected data in 2006–2007 from adolescents with a borderline, mild, moderate, severe or profound ID aged 12–18 years living in two provinces in the north of the Netherlands, Groningen and Drenthe (total population of about 1.1 million people). Adolescents of the target population attended secondary schools, special secondary schools, day care centers or lived in residential centers. ID-adolescents attending secondary schools can be classified as mainly educable and have IQs between 60 and 84. ID-adolescents attending special secondary schools can be classified as mainly trainable and have IQs between 30 and 59. ID-adolescents not attending school, most of them with IQs < 30, attend day care centers or live in residential centers (Dekker, Koot, van der, & Verhulst, 2002). The target population had been officially classified as having ID by two independent committees. The Dutch Ministry of Education, Culture and Science established a committee for adolescents attending secondary or special secondary schools and the Dutch Ministry of Health, Welfare and Sport established a committee for adolescents attending day care centers or those living in residential centers. The classification of ID is based on the information from validated intelligence tests obtained by both committees (Care Assessment Centre, 2009; Dutch Eurydice Unit, 2007).

In the current community-based cross-sectional research project, 70% of the schools and centers in both the provinces participated, with a total of 2271 adolescents. Non-participating schools and centers did not differ from participating schools and centers with regard to urbanization of the catchment area and number of adolescents. All parents of the 2271 adolescents aged 12–18 years received a questionnaire and a reminder when they did not respond; 1083 parents returned the questionnaire (48%). Adolescents in the response and non-response group did not differ with regard to age (t -test = 1.86, $p > 0.05$), but in the response group girls ($\chi^2 = 4.35$; $p < 0.05$) and adolescents with borderline or mild ID ($\chi^2 = 8.96$; $p < 0.05$) were somewhat overrepresented. However, the effect sizes for both the variables were negligible; Cohen's w were 0.05 and 0.07, respectively (Cohen, 1988).

The study protocol was approved by the Medical Ethics Committee of the University Medical Center Groningen, the Netherlands.

2.1.2. Adolescents in the general population

Statistics Netherlands conducts yearly the National Permanent Survey on Living Conditions (POLS) questionnaire in a representative sample ($n \approx 10,000$) of the Dutch population (Otten & Winkels, 1998). We used the data, adjusted for non-response, on adolescents aged 12–18 years in 2007 (Statistics Netherlands, 2009) (response: 64%). Prevalence data on chronic diseases in adolescents in the general population that were not available via Statistics Netherlands were derived from the National Institute for Public Health and the Environment (NIPHE). The NIPHE provides national and international

data to support policymakers and professionals in various fields of work such as prevalence rates of chronic diseases (National Institute for Public Health and the Environment, 2009).

2.2. Measures

2.2.1. Chronic diseases in ID-adolescents

Chronic diseases in ID-adolescents were measured by the National Permanent Survey on Living Conditions (POLS) questionnaire; module health and labor, part chronic diseases in children (Statistics Netherlands, 2003). POLS part chronic diseases in children covers the most prevalent chronic diseases such as ear, eye, skin diseases, diseases of the nervous, musculoskeletal, blood and circulatory, respiratory, digestive, and endocrine, nutritional and metabolic systems and attention deficit hyperactivity disorder (ADHD). Questions were added about the presence of pervasive developmental disorders (PDD). Parents were asked to fill in the presence or absence of each specific chronic disease in the last 12 months for their child. Parents were also offered the possibility to mention chronic diseases that were not listed in the questionnaire.

2.2.2. Chronic diseases in adolescents in the general population

The prevalence rates of chronic diseases in adolescents in the general population were measured in the same way as in our study, using the POLS questionnaire. Prevalence rates of chronic diseases in adolescents in the general population that were not available in POLS were obtained from the NIPHE. The NIPHE data are based on national and international research (National Institute for Public Health and the Environment, 2009).

2.2.3. Background characteristics of ID-adolescents

The questionnaire in the ID-adolescents sample comprised questions on age, gender and type of school or institution the adolescent is attending. We used type of school or institution as a proxy for severity of ID.

2.3. Analysis

First, we computed prevalence rates and the 95% confidence intervals (95%CI) of having one or more chronic diseases, overall and by type of chronic diseases. The association between the number of chronic diseases and ID severity and gender were assessed via univariate analysis of variance parameter estimates. Second, we performed multinomial logistic regression analyses. Odds ratios (OR) and their 95% confidence intervals (95%CI) were computed to assess the association between the occurrence of chronic diseases by type, and ID severity and gender. Third, we computed prevalence rates of separate chronic diseases in ID-adolescents, and compared these rates with rates among adolescents in the general population (12–18 years) (Statistics Netherlands, 2009). We tested differences using chi-square tests. If national data were not available from Statistics Netherlands, we used data from the NIPHE instead (National Institute for Public Health and the Environment, 2009). Differences were tested via single proportion tests. For all the differences in proportions, effect sizes according to Cohen were calculated (Cohen, 1988). Cohen (1988) defines an effect sizes of <0.20 as trivial effects; of ≥ 0.20 to <0.50 as small effects; of ≥ 0.50 to <0.80 as moderate effects; and of ≥ 0.80 as large effects.

3. Results

Table 1 shows the background characteristics of the adolescents. The gender ratio, 58.3% boys and 41.7% girls, was similar to the ratio of boys and girls with ID in the Netherlands (Van Schrojenstein Lantman-de Valk et al., 2002).

Table 2 shows that 63% of the ID-adolescents had at least one chronic disease and 34% had two or more chronic diseases (mean 1.30; SD 1.47). Thirty-nine per cent of the ID-adolescents had one or more somatic chronic diseases and 41% had one or more mental chronic diseases. Out of these, 20% had a combination of somatic and mental chronic diseases.

Table 1
Demographic characteristics of the sample.

| Age in years (N = 1066) | Years |
|--|------------|
| Mean (SD) | 15.4 (1.6) |
| Range | 12–18 |
| Gender (N = 1074) | n (%) |
| Boys | 626 (58.3) |
| Girls | 448 (41.7) |
| Severity of ID ^a (N = 1077) | n (%) |
| IQ 60–80 (mild ID) | 785 (72.9) |
| IQ 30–59 (moderate ID) | 253 (23.5) |
| IQ < 30 (severe ID) | 39 (3.6) |

^a Derived from the type of institution at which they were allocated.

Table 2

Number and type of chronic disease(s) and 95% confidence intervals in ID-adolescents.

| | ID-adolescents (N = 1083) | | |
|--|---------------------------|------|----------------|
| | n | % | 95%CI |
| Number of chronic diseases | | | |
| 0 | 402 | 37.1 | (34.29; 40.04) |
| 1 | 313 | 28.9 | (26.28; 31.67) |
| 2 | 178 | 16.4 | (14.35; 18.77) |
| 3 | 97 | 9.0 | (7.40; 10.81) |
| 4 | 56 | 5.2 | (4.00; 6.65) |
| 5–11 | 37 | 3.4 | (2.49; 4.68) |
| Type of chronic diseases | | | |
| None | 402 | 37.1 | (34.29; 40.04) |
| Somatic chronic disease(s) | 235 | 21.7 | (19.35; 24.25) |
| Mental chronic disease(s) | 245 | 22.6 | (20.23; 25.21) |
| Somatic & mental chronic diseases in combination | 201 | 18.6 | (16.36; 20.99) |

Gender and severity of ID were associated with these prevalence rates. Gender was not associated with the number of chronic diseases, but boys were more likely than girls to be diagnosed with mental chronic diseases (OR 2.23; 95%CI 1.57–3.16) and with a combination of somatic and mental chronic diseases (OR 1.47; 95%CI 1.03–2.10). Severity of ID was positively associated with the number of chronic diseases ($F=48.12$, $p<0.000$). With regard to the type of the chronic diseases, adolescents with severe and moderate ID were more likely than adolescents with mild ID to be diagnosed with somatic chronic diseases (OR (95%CI) 12.35 (2.70–55.56), and 3.31 (2.04–5.00), respectively), mental chronic diseases (9.00 (1.91–41.67), and 1.88 (1.22–2.86), respectively) and a combination of somatic and mental chronic diseases (25.00 (5.62–111.11), and 3.85 (2.56–5.88), respectively). In addition, adolescents with severe ID were more likely than adolescents with moderate ID to be diagnosed with a combination of somatic and mental chronic diseases (6.44 (1.43–29.14)).

Table 3 shows that the prevalence rates of chronic diseases among ID-adolescents were statistically significant higher for 8 of the 17 chronic diseases compared to the prevalence rates of these chronic diseases in adolescents in the general population. The effect sizes were negligible for two (asthma, chronic bronchitis and COPD, and psoriasis) of the four somatic chronic diseases that differed with statistical significance, and small for the three other ones (epilepsy, heart diseases, and blood diseases). With regard to mental chronic diseases, the effect sizes for the statistically significant differences were small for dyslexia and medium for ADHD, PDD-NOS and autistic disorder.

4. Discussion

This study shows high prevalence rates of a wide range of chronic diseases in ID-adolescents. For 8 of the 17 chronic diseases that we assessed the prevalence rates were statistically significant higher among ID-adolescents than among adolescents in the general population. Differences were particularly large with regard to ADHD, autistic disorder, and PDD-NOS, and smaller for some somatic diseases. Moreover, differences in prevalence rates were larger if ID was more severe, with regard to any mental chronic diseases and with regard to a combination of any somatic and any mental chronic diseases.

4.1. Fit with other studies

Our findings regarding adolescents cannot be compared with previous ones on adolescents because our study was the first that examined the prevalence rates of a wide range of chronic diseases in ID-adolescents, and compared them with the prevalence rates among adolescents in the general population. Previous studies on youth with ID also found higher prevalence rates of a wide range of mental chronic diseases (Emerson & Hatton, 2007; Emerson, 2003; Magnusson & Saemundsen, 2001; Voigt et al., 2006) and a wide range of congenital malformations (Pettersen et al., 2007) though. However, these studies did not separately report on adolescents, thus failing to recognize adolescence as a specific developmental stage. It is likely that this explain the differences in the prevalence rates of mental chronic diseases and congenital malformations these studies found compared to our study.

Three factors have been proposed to explain the high rates of chronic diseases in the ID population in general. First factor is biological/genetic, i.e. genetic and chromosomal disorders that cause both ID and a wide range of chronic somatic and mental diseases (Dykens, 2000; Emerson & Hatton, 2007; Koskentausta et al., 2002). Second, the association of ID with socio-economic disadvantage may lead to adverse health outcomes and to higher rates of chronic diseases (Cooper et al., 2004; Emerson & Hatton, 2007; Emerson & Hatton, 2008; Walsh, 2008). Third, mental chronic diseases may be associated with ID because they share diagnostic characteristics (Dykens, 2000; Emerson & Hatton, 2007).

Table 3

Prevalence rates of chronic diseases in adolescents with ID and in the general population.

| | ID-adolescents | | General population | | Differences | |
|---|----------------|----------|--------------------|---------|-------------------|---------------|
| | % | n/N | % | n/N | p-Value | Cohen's h^a |
| Somatic chronic diseases | | | | | | |
| Asthma, chronic bronchitis, COPD ^b | 9.9 | 107/1083 | 6.2 | 30/481 | 0.019 | 0.13 |
| Chronic eczema ^b | 4.3 | 47/1083 | 2.6 | 14/536 | n.s. ^c | 0.09 |
| Diabetes ^b | 0.5 | 5/1083 | 0.4 | 2/498 | n.s. | 0.01 |
| Gastrointestinal and liver diseases ^b | 1.8 | 19/1083 | 1.0 | 4/396 | n.s. | 0.06 |
| Migraine or chronic headache ^b | 12.7 | 138/1083 | 11.5 | 52/452 | n.s. | 0.04 |
| Musculoskeletal diseases ^b | | | | | | |
| Diseases of the back ^b | 2.6 | 28/1083 | 2.7 | 14/517 | n.s. | 0.01 |
| Inflammatory polyarthropathies ^b | 0.8 | 9/1083 | 0.4 | 2/442 | n.s. | 0.05 |
| Diseases of neck, shoulder and upper extremities ^b | 5.3 | 57/1083 | 3.3 | 14/430 | n.s. | 0.10 |
| Psoriasis ^b | 1.3 | 14/1083 | 0.1 | 1/519 | 0.030 | 0.14 |
| Heart and blood diseases ^b | 2.4 | 26/1083 | 0.1 | 1/524 | 0.001 | 0.22 |
| Congenital malformations circulatory system ^d | 2.1 | 23/1083 | 0.62 ^e | – | n.s. | 0.13 |
| Congenital malformations nervous system ^d | 2.0 | 22/1083 | 0.21 ^e | – | n.s. | 0.19 |
| Epilepsy ^d | 5.3 | 57/1083 | 0.27 ^f | – | 0.000 | 0.36 |
| 95%CI | | | | | | |
| Somatic chronic diseases no reference data available | | | | | | |
| Congenital malformations eye | 3.0 | | 32/1083 | | | (2.10; 4.14) |
| Congenital malformations ear | 1.8 | | 20/1083 | | | (1.20; 2.84) |
| Chromosome abnormalities | 3.5 | | 38/1083 | | | (2.57; 4.78) |
| Cerebral palsy | 0.5 | | 5/1083 | | | (0.20; 1.07) |
| Muscular diseases | 0.7 | | 8/1083 | | | (0.38; 1.45) |
| Other congenital malformations | 6.1 | | 66/1083 | | | (4.81; 7.68) |
| Other somatic disorders | 3.7 | | 40/1083 | | | (2.72; 4.99) |
| | % | n/N | % | n/N | p-Value | Cohen's h^a |
| Mental chronic diseases | | | | | | |
| Dyslexia ^b | 13.9 | 151/1083 | 3.8 ^g | 87/2285 | 0.000 | 0.37 |
| Attention deficit/hyperactivity disorder (ADHD) ^d | 21.1 | 229/1083 | 1.3 ^h | – | 0.000 | 0.73 |
| Autistic disorder ^d | 10.9 | 118/1083 | 0.1 ⁱ | – | 0.000 | 0.61 |
| Pervasive developmental disorder not otherwise specified (PDD-NOS) ^d | 14.0 | 152/1083 | 0.2 ⁱ | – | 0.000 | 0.68 |
| 95%CI | | | | | | |
| Mental chronic diseases no reference data available | | | | | | |
| Other psychiatric disorders | 1.8 | | 19/1083 | | | (1.12; 2.72) |

Bold results are statistically significant.

^a Cohen thresholds: negligible effect (≤ 0.20); small effect (≥ 0.20 and < 0.50); medium effect (≥ 0.50 and < 0.80); large effect (≥ 0.80).^b Reference data on adolescents aged 12–18 from Statistics Netherlands (POLS).^c Not significant.^d Reference data from the National Institute for Public Health and the Environment.^e Only data at birth available.^f Only data on the age-group 15–24 years available.^g Only data on the age-group 4–12 years available.^h Only data on the age-group 13–17 years available.ⁱ Prevalence data estimated on the basis of the review of Fombonne (2005) on autistic disorder and other pervasive developmental disorders.

4.2. Strengths and limitations

Important strengths of this study are that it examined the prevalence rates of a wide range of chronic diseases in ID-adolescents in a community-based sample representative for about 90% of the adolescents with ID, and compared most outcomes with similarly obtained data on adolescents without ID. A limitation may be that data collection procedures may have slightly differed between adolescents with ID and in the general population. POLS did not cover mental disorders other than ADHD, we used data of the NIPHE instead. However, the differences in prevalence rates were so large that they are unlikely to be fully explained by methodological differences. A second limitation is the relatively low response rate of our study (48%). This could lead to selection bias, but non-response analyses revealed no major differences with regard to age, gender and educational level.

4.3. Implications

We found disconcertingly high prevalence rates for some chronic diseases among ID-adolescents which should alert policymakers and clinicians to these diseases among ID-adolescents. This shows a need for effective care arrangements to handle this huge burden of morbidity, both with regard to its prevention and its treatment. As such, it provides a challenge to

both clinicians and policy (American Association on Mental Retardation, 2002; Goddard et al., 2008; McDermott et al., 2007; Newacheck et al., 2006).

Our study is the first to examine the prevalence rates of a wide range of chronic diseases in ID-adolescents and compare the results with data on adolescents without ID. Therefore, our findings need confirmation, including an assessment of the pathways leading to such high prevalence rates. Anyhow, our results show a very high burden of chronic diseases among ID-adolescents, and thus adequate care is highly needed (Cooper et al., 2004; Van Schrojenstein Lantman-de Valk & Walsh, 2008).

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